

## Report on UK Visit 2016



## Living Well With Dementia Reflections from Tomo, Eiko and Dr Yamazaki (Translated by Dr Mayumi Hayashi FRSA)

認知症とともに、よく生きる旅へ

Published by: Miyagi 'Dementia Discussion Group' Association and Miyagi Dementia Working Group 2017

Miyagi 'Dementia Discussion Group' Association, Japan (2017)

Contact : office-e@lwdmiyagi.jp

To download free copies go to : <https://miyaginintishou.jimdo.com/>

# Contents

<i>Acknowledgements</i>	3
<i>Preface</i>	4
<i>Yuji Kawamura</i>	
• <b>A journey of living with dementia</b>	<b>5 – 34</b>
<i>Tomofumi Tanno</i>	
• <b>What I learnt from accompanying Tomo on his UK trip</b>	<b>35 – 37</b>
<i>Dr Hideki Yamazaki</i>	
• <b>Comments from Tomo's partner on the UK visit</b>	<b>38 – 39</b>
<i>Eiko Wako</i>	

## ***Acknowledgements***

This report stems from a visit to the UK in September 2016 led by Tomofumi Tanno, a person living with dementia and his 'partners' from the Miyagi 'Dementia Discussion Group' Association, Japan (Dr Hideki Yamazaki and Eiko Wako) together with Yuji Kawamura and his NHK TV crew, Nagata Kumiko (Dementia Care Research & Training Center, Tokyo) and Dr Mayumi Hayashi FRSA (ECRED, University of Edinburgh).

We would like to acknowledge and thank all the people who made this trip and subsequent Report possible. Specifically, we thank James McKillop, Agnes Houston and Wendy Mitchell (Tomo's UK friends who are living with dementia). We also thank the following people: Philly Hare, Steve Milton and Damian Murphy (Innovations in Dementia CIC and the Dementia Engagement & Empowerment Project [DEEP]); Professor Heather Wilkinson, Liz Taylor and Julie Watson (ECRED, University of Edinburgh); members of the Scottish Dementia Working Group and the Alumni; Emily Abbot and members of York 'Minds & Voices' group; Jim Pearson and colleagues (Alzheimer Scotland); Anna Buchanan and colleagues (Life Changes Trust); Stephen Lithgow and colleagues (NHS Health Care Improvement Scotland); all participants in the Memory Walk (Alzheimer's Society).

Special thanks to Kumiko Magome and Kumiko Watanabe whose negotiations with the Scottish Dementia Working Group contributed to the success of the trip. Additionally, special thanks go to Hirofumi Inoue who designed and formatted this Report so beautifully, and to Dr Mayumi Hayashi FRSA for translating this Report in its entirety.

## ***Preface***

Yuji Kawamura, NHK Director (Japan Broadcasting Corporation)

This Report is a record of the twelve-day visit to the UK on the 18<sup>th</sup> September 2016 by Tomo and his companions. The visit produced many discoveries and insights about the possibility of ‘living well with dementia’ for Tomo and his companions. I feel that this will provide new horizons for living well with dementia in Japan in the future. In fact, Tomo and his companions have started a series of plans and actions since their return to Japan.

The origins of the UK visit stem from the appearance of James McKillop, the founder of the Scottish Dementia Working Group, and his wife at the Forum in Japan in November 2015.\* On that occasion, Tomo also appeared at the Forum and met James. This encounter moved Tomo profoundly. On stage, Tomo stated that ‘I admire James as a man’, and after the Forum he declared that ‘I will go to Scotland and see James’. However, there was no clear idea where to go or what to do. In this context, in June 2016 Professor Heather Wilkinson from the University of Edinburgh and Philly Hare from Innovations in Dementia CIC paid successive visits to Japan. Dr Mayumi Hayashi from the University of Edinburgh accompanied and supported both of them throughout their visits during which Heather and Philly met Japanese people living with dementia – including Tomo – and the continuation of the collaborative relationship was discussed. As a first step, the September 2016 UK visit was undertaken. If I could sum up Tomo’s trip: it was a series of encounters and dialogues between Tomo and people living with dementia in the UK. Through these encounters and dialogues, Tomo and his friends were greatly surprised on many occasions and learnt a great deal. Expressing their gratitude to all those they met during the trip and hoping to build the foundations for future exchanges and collaborative relationships, this Report was produced.

\*For details, see: <http://www.careinfo.org/wp-content/uploads/2012/05/12-13JDCMJ16.pdf>

## A journey of living well with dementia

Tomofumi Tanno, Miyagi Dementia Working Group;

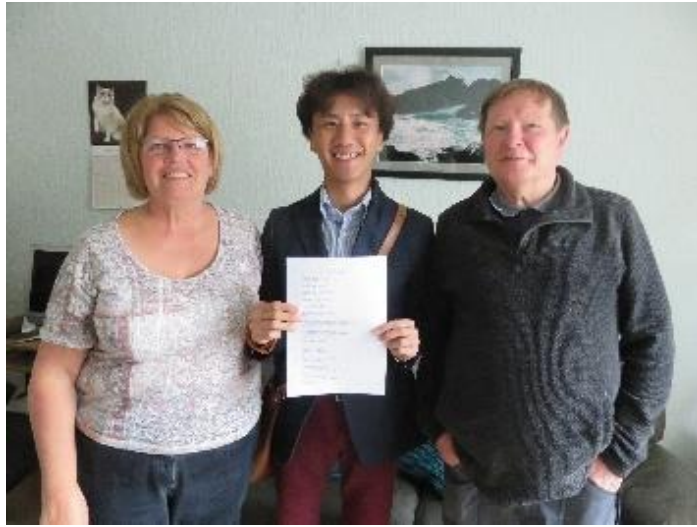
Miyagi 'Dementia Discussion Group' Association



Photo: Alzheimer's Society

## Why? Why did I want to go to Scotland?

Last year, I met James McKillop from the Scottish Dementia Working Group and learnt from him that although there were differences between Japan and Scotland and their environments, there were many similarities for people living with dementia including anxiety and fear following a diagnosis of dementia and remaining house-bound due to the fear of stigma – which gave me a feeling of empathy.



Photos: Yuji Kawamura

In Scotland, people with dementia speak up for themselves and there are many groups of people with dementia. How did such groups come about? Why did people with dementia speak up for themselves? I thought that what was successful in Scotland might also be relevant for Japan.

And, I was attracted by the kindness and gentleness of James and I wanted to meet James again as a man I can look up to – not only as a person with dementia.

I thought that it was important that researchers went to see - but I thought that it was also important for people with dementia to go see and feel.

## **My journey to the UK: discovering a difference**

When I went in September 2016 I was able to meet many people with dementia and to listen to their stories. My visit to the UK in September was the first for me so far to meet and listen to so many people with dementia.

At first, I was continuously asking about stigma and support. However, as I met and talked with people with dementia I started to feel that there were differences between them and Japanese people with dementia.

This difference was that the people with dementia I met – even though their dementia progresses – they had a strong desire to do things by themselves and that supporters around them are aware of only giving the minimum support to sustain their independence. When I realised this I started to wonder what living with dementia could be like?



Photo: Yuji Kawamura



Photo: Yuji Kawamura



Photo: Hideki Yamazaki

## **Action groups of people with dementia in the UK**

First of all, I would like to talk about campaigning/action groups of people with dementia (such as the Scottish Dementia Working Group) in the UK.

There are groups of people with dementia across the communities in the UK, totaling about 60 such groups in all.

I understand that many of these groups are small-sized.

Such groups were set up with the wish to meet and talk within their local vicinity.

The member size of many groups is 5-10 people and most people with dementia come to the meetings alone.

People with dementia chair the meetings at which everybody talks while seated at the round table. Everywhere I attended such meetings, people often laughed and joked and there was a happy, jolly atmosphere.

They said that because it was a happy place people gathered naturally.

However, even in Scotland there is a reality that only a proportion of people with dementia come to the meeting and the majority remain house-bound.





Photos: Yuji Kawamura

### **Joining in the Scottish Dementia Working Group and Alumni in Scotland**

I said that in Japan there is a reality that people do not want to come to the meeting because of the stigma – so I asked them why did they feel able to participate? They replied that although there is a stigma in Scotland they came because it was fun.

They said that by coming and talking they got confidence and that by informing the public that despite having dementia there are still things that they can do, there has been a change which is that they

are becoming increasingly respected by those around them.

They said that their families were proud of them and did not stop them from coming to the meetings and doing these things.

It is now 15 years since people with dementia spoke up for themselves. At first there was only James McKillop.

They said that by seeing James talking before the public they said that they too wanted to do the same – and this spread like a virus.

In the Scottish Dementia Working Group the members started to give talks to small numbers in the vicinity and individuals were supported to give longer talks.

At the meetings, they discuss only one theme and when they wish to discuss another theme it is arranged for the next meeting.

In the discussion there was a method of enabling speakers by the use of a system of cards.

There were three cards: I Want To Speak; Slow Down; I Need Help.



Photo: Yuji Kawamura



Photo: Kumiko Nagata



Photo: Yuji Kawamura

I learnt that it was essential to make it clear that on that day the members had come to discuss this particular theme.

Often, supporters did not join in the conversation but simply made sure that at the end they provided a recap. I felt that people with dementia took control and did everything.

I understood that it was natural for supporters who had studied dementia to come to the meetings rather than having to be tasked to do so.

So I thought that back in Japan I would have to increase such supporters – initially from my community.

Additionally, they said that there was a role for so-called ‘co-opted members’ who give advice when people with dementia cannot make decisions.

In the SDWG people with dementia interview potential supporters (co-opted members) who will carry out the role for three years and who are people experienced in dementia such as those from Alzheimer Scotland.

It seems that because people with dementia are running the Group, they decided that three, not more, supporters (co-opted members) would be sufficient.

## **Joining in the Minds and Voices group in York**

The reason that there are as many as 60 groups in the DEEP network is due to a person like Philly who has a clear understanding of the philosophy, and numbers of such groups grew with greater interaction between the groups.

Although each individual group is small, the meetings are held locally so that there are no large expenses such as transport.

As they use community resources for their meeting venue it is easy to hold meetings about once a month.

Because there are many small groups, next week they can try to participate in a nearby group. So anybody can go to any meetings which is the advantage of doing things within their own communities.

And, I remember that the members in Scotland had been very solicitous and they themselves had worked to host the meeting.

They made coffee, they opened windows to refresh the airflow and indicated the toilet facilities.

I thought that although these things were ordinary for the members to do they showed us that they themselves were doing these things confidently and they taught me that at meetings it was important to listen to other people.





Photos: Yuji Kawamura

## **'Independence' in Scotland and Japan**

Next, I would like to talk about independence.

It was said that in Scotland there were three ideas about supporting people with dementia:

- Eliminating stress
- Eliminating anxiety
- Supporting independence

I feel that in Japan the equivalents to these three ideas are:

- Eliminating stress
- Eliminating anxiety
- Protecting = doing things for them

In Scotland people with dementia say that even though their dementia progresses they want to continue to do things for themselves.

And I felt that there is a difference between Japan and the UK towards the way people surrounding them support people with dementia and the attitudes of people with dementia regarding their lifestyles.

When thinking about independence, the important points are: making decisions for themselves; whether they are living the lives they wish to have; and whether they are living their 'own' lives.

I feel that it is important that we people with dementia are not being protected but should overcome challenges in order to achieve our goals with the help of supporters.

Although there are risks involved, being protected leads to a decline in our functions.

## **Technologies supporting independence: GPS**

There are many technologies and arrangements which support independence which I would now like to introduce.

The first is GPS. A person came on his own to a meeting wearing a GPS. I asked him for whom he was wearing it. He replied that it was for both himself and for his wife.



Photo: Yuji Kawamura



Photo: Tomofumi Tanno

He said that he gets lost, so by wearing the GPS it can reduce the anxiety if something happens. Because he attaches it himself he does not forget to wear it.

In Japan, GPS is attached to the wearer but in Scotland they attach it themselves before going out. I do not understand but he was wearing three GPS units.

## **Technologies supporting independence: More examples**

The next item is a watch. Agnes for example was wearing one and she told me that although she cannot read the figures on the watch when she presses a button an audio time is given. She told me with a smile that she would prefer to have a more stylish watch.



Photo: Kumiko Nagata

Additionally, she was carrying her pill box which gives an alert when it is time to take the next medicine – so she does not forget to do so. These items were not given freely but she herself bought them.



Photo: Tomofumi Tanno

This is a telephone which I saw in a university department which researches dementia friendly everyday-living items among other topics.



This telephone has family snaps attached and you can press the pre-dial button underneath of the snaps of the person you wish to talk to. As it is a photograph rather than numbers, you can see it instantly at a glance.

The signage for the toilet is presented as a picture and is attached near to the door-knob which I found easy to understand.



Photo: Kumiko Nagata

This is the fridge with a transparent door. Because you can see inside all the time it has the effect of preventing buying things repeatedly.



Photo: Kumiko Nagata

Also, there are arrangements for toilets, toilet seats, doors and stairs through using different colours to make it easier to understand for people with dementia.

## Meeting Wendy at home near York, England

This picture shows Wendy, a person living alone with dementia, whose house I visited.



Photo: Yuji Kawamura

Wendy forgets what there is in her wardrobes and cupboards and becomes anxious so she takes photos of the contents and places these on the outside doors.

By knowing what is inside, it appears that her stress and anxiety are reduced.



Photo: Yuji Kawamura

In order to avoid forgetting to take her pills, she places the pills next to the teapot where she takes tea in the morning and the stairs when she goes upstairs to bed at night.



Photos: Tomofumi Tanno

She said that she uses two calendars – weekly and monthly – in order not to forget.



Photo: Tomofumi Tanno

## Meeting a proud man with his Land Rover

This picture also shows Stuart, a Scotsman living with dementia. He showed me his Land Rover of which he is proud. He still drives it.



Photo: Kumiko Nagata

I learned that for Driving Licenses, as long as you pass the test it is OK to drive even with a diagnosis of dementia.

He said that it helps him to have a driver's license because he lives in the country and his hobby is fishing and there are lots of difficulties arising out of not having a car.

In Scotland, people with dementia are living their lives with some risk-taking and their families do not restrict them and are proud of such people with dementia being so confident.

The people with dementia in Scotland do experience progression of their dementia but they know that even with such progression they can remain OK by making certain individual arrangements.

By doing things for themselves they remain confident.

However, this does not apply to everyone with dementia but only to a proportion of them who continue to live independently.

This proportion continue to remain lively and smiling even after ten years of living with dementia.

These are the words of Stuart.

- Supporting independence can be achieved by being open about dementia.

- By eliminating stigma, it is important that individuals are open about dementia.

- Dementia is not embarrassing – even though you are intelligent you might develop it.

- People say how sorry they are for me – but I am living well with dementia.

- I want to eliminate stigma. In order to do so, it is important to keep repeating that dementia is not embarrassing.

I felt that the people with dementia I met do not give up anything and they retain hope as their disease progresses.

## Getting to know the Link Worker System

Now I would like to talk about Link Workers in Scotland.

Link Workers always ask people with dementia this question: “*What do you want to do?*”

And then they plan in order to realise this.



Photo: Yoko Oshima



Photo: Hideki Yamazaki

For me, after my diagnosis of dementia, I have never been asked “What do you want to do?” and I only have memories of how to use the public long term care and support services being explained to me.

I met people in the Non-Profit Organisation, Miyagi Dementia Movement Consultation Group, and went with them on an overnight trip to Kyoto. Afterwards, I felt that I can still enjoy doing such fun things with them.

Before that, I think that I gave up because I ‘had dementia’.

I think that planning and realising together with a person with dementia, a Link Worker can get to know them and understand what they need – and journey alongside them and build the feelings of trust.

In Japan, conversations still tend to be one-way with a Care Manager who talks only about the use of public long-term care services and support and direct them to such services so there is no

opportunity to build up a relationship of trust.

And the conversation is not held with the person with dementia but is an explanation to the family.

I do not think that we urgently need the Scottish Link Worker system in Japan.

In Japan we already have community one-stop centres for integrated care and support for the entire older population. I think that if staff there can change their attitude towards people with dementia they can play the same role as Link Workers.

They would then listen not to families but to people with dementia and they would not connect with support services straightaway but try to ascertain what the person with dementia needs – and how to attain it together.

When I talk about this you might probably say that this is just common sense.

However, the reality is that this common sense is absent.

### **What we really want to do**

Now I want to talk about the discussion at the follow-up training of Dementia Friends Champions (we call them 'Mates' in Japan).

The discussion is about 'What do you want to do when you receive a diagnosis of dementia?'

The answers included 'going for a walk' and 'amusing myself in the park'.

I think these wishes can be realized easily and quickly.

Will you really want to go for a walk if you develop dementia in the future?

If it was me I would not want to go for a walk but would want to go out with a purpose such as 'shopping' or 'going to the cinema'.

Also if I amuse myself I would like to do this not in the park but in the

UFJ (theme park) or Disneyland.

Even if I grow old I would like to go on a hot springs trip.

This is because when I am with Mrs Wako (my 'partner' or supporter who is over sixty-five) I felt that even though she is growing old she still wants to amuse herself.

This is the reality: once you get a diagnosis of dementia Mates think that you cannot do such things and Mates think that people with dementia themselves believe the same.

Please ask yourselves and think whether such Mates can build trusts or can they travel alongside the person with dementia.

### **Realising personal goals with a Link Worker**

Back in Scotland, a Link Worker for this person with dementia pictured seated in the middle below supported him to realise his wish to go horse riding and to visit Alaska.



Photos Yuji Kawamura

I do hope that in Japan we have an increase in people who don't just focus on whether you can do things – or not – but consider how you can do it; believe that you can do it; and think jointly about how to realise it.

## Joining in a Memory Walk in Leeds

Now I would like to talk about the Memory Walk.

I participated in the Memory Walk. This is a 'dementia awareness' event.



Photo: Alzheimer's Society

We walked from 2 to 6 kilometers and about 3500 people – including small children, older people and quite probably people with dementia – gathered together and walked in happiness.

You can see that they were enjoying it just like a festival.



Photo: Yuji Kawamura

During the walk, each individual attached signs to themselves making it clear why they were walking.

When I spoke to children they replied very clearly that they were walking for 'My Uncle' or 'My Grandma' who had dementia – or 'My friend's Grandma.'



Photo: Yuji Kawamura

In Japan, when there was such an event, children were taken to it but did not know why - so I felt very impressed with this Memory Walk in Leeds.

It appears that 'I was walking for my Grandma so please donate' suggests that the event was a charity fundraiser.

In contrast, the Mums said that 'By the time our children are adults, there would be drugs to cure dementia so I am willing to donate.'

In Japan, I felt that we do fundraising when natural disasters happen or to help ill people - but we do not donate for the future.

Those who attended the Memory Walk do not hide the fact that they have relatives who have dementia.

I thought that by having held Memory Walks in different places, there is already a social environment in which people can be open about dementia.



Photos: Yuji Kawamura

This celebrity cut the tape and completed the Memory Walk – and supported the event by distributing medals to participants at The Finish; shaking hands and standing for photos until the very end. When I saw this I thought that this was ‘real’ support – not just tokenism.



Photos: Yuji Kawamura

## My commitments in my hometown Sendai, Japan

From now on, I am going to share my thoughts about what I should do in Sendai based on my experiences and learning in Scotland and the UK.

### Continuity of 'Orange Door'.

In Sendai, I set up the 'Orange Door' as a gateway in May last year. This is a gateway – not a meeting place (Ibasho).



Photos: Miyagi 'Dementia Discussion Group' Association

This is a door through which a person just before or immediately after a diagnosis of dementia can take their first steps.

This is a place where a person with dementia meets another person with dementia with a smile – by which you feel you can take your first steps.

This place has the role of connecting visitors with meeting places, places for support – and doctors.

The 'Orange Door' is not like existing information points and it does not just connect to local resources but it connects to resources

where Orange Door members are also involved – giving a sense of safety.

Because visitors to the Orange Door come once or twice before being connected to other local resources – such as a meeting place – we need to have new comers constantly.



Photo: Miyagi 'Dementia Discussion Group' Association

### **What should 'meeting places' in Japan be like?**

When it comes to meeting places (Ibashos) there are many different places such as 'peer-support' and cafes.

In these places, people with dementia became positive through talking among themselves and their families.

They can also get advice. These are the places for people with dementia to do things and to talk among families and supporters.

Because these are meeting places (not the Orange Door) people with dementia can stay even though their dementia progresses.

However, there are meeting places which are completely joyless – as are some dementia cafes. It is necessary to make such dementia cafes places where people with dementia want to visit.

*So what kind of cafes do you wish to visit?*

If you are women, it might be where you can enjoy a 'girls-talk' with delicious cakes and teas. If it was me, I want a Gundam café and 'comic cafes' featuring One Piece.

For baseball fans, it might be a place where people can watch baseball together.

I think that it is good to have different places and that they should not all be the same.

I feel that now is the time to think about whether the meeting place that you are organising is really a place that you yourself want to visit.

And by making the meeting places somewhere where you feel very comfortable, you are creating different meeting places - so that people with dementia can choose and visit.

If there are meeting places, I feel that this will stop the custom of being encouraged to use the public long-term care services immediately and consequently reduce the usage of these services.



My visit to the Aroma Coffee Shop in York

Photos: Yuji Kawamura

## **From meeting groups to action groups**

Once you feel positive after visiting meeting places you can see gradually that it might be helpful if you had a new support system or you identify inconveniences in your community.

I do hope that people with dementia who realise that they themselves want to do something about these!! or let others know about these!! will progress to the next step and join in an 'action group' (a dementia working group).

## **Creating the Sendai Working Group**

Now we are creating the Sendai Working Group as a platform to speak out to society.

This is the platform for speaking out to society – not a meeting place.

This platform is where people with dementia discuss and speak out to society and therefore this platform plays a role in making changes in the community – and the nation.

This is the place where people with dementia, who have a clear intention to want to tell their stories – come together and discuss according to the set themes.

Until these were created there were only meeting places, so if there were places / groups other than these meeting places I thought that it would be difficult to see differences between them.

Even though I say they are not meeting places – but it still remains easy for them to be mistaken as meeting places – so I think that it is important to make this clear. Unless this difference is repeatedly emphasised, it becomes blurred.

I think that I would like to share with you what we have talked about – and also speak out to society.

*Why do we need a Working Group in Sendai?*

We can leave speaking out to society to the Japan Dementia Working Group, can't we?

No, we can't, because I learned from Scotland that we need to change the immediate community and was told that people with dementia thought it necessary to have dementia friendly *streets* rather than dementia friendly *communities*.

With groups of people with dementia growing out of their community, there are now sixty such groups across the UK.

I thought that I would have to make a dementia friendly society within my neighbourhood.



Photo: Miyagi 'Dementia Discussion Group' Association

### **Why we need a dementia friendly society?**

So, why do we aim to create a dementia friendly society? Not create a society without dementia?

This is my opinion. It will be possible that we will discover drugs to eliminate dementia.

If dementia is eliminated, we still cannot prevent ourselves from growing old, I believe.

I think that dementia and growing old is the same in terms of a decline in functions.

So, if society becomes dementia friendly, even though dementia is eliminated, this society will be age friendly.

When we aim to create a society without dementia, when dementia is eliminated, then we might have a campaign to eliminate older people, I feel.

Is it because I watch Anime too much?

### **What will I do?**

Now I am going to tell you what I will do.

- Even though my dementia progresses I will not hide the condition.
- I will not hide what I cannot manage to do. I will be open about this and will receive support.
- I will keep having the intention to think creatively and make arrangements to continue to do things by myself.
- I will live happily – with a smile.

If I say anymore it will become too compressed so I will do these things in a more relaxed manner.

### **What will you do?**

Now I am talking about what those of you who have not yet got dementia will do.

- To treat dementia as being your own business.
- To think together with people with dementia and live happily together.

## **What does 'living with dementia' mean?**

I have a fear about the progression of my dementia in the future. However, even though it progresses, if with support I can live happily from moment to moment – this is what living with dementia means following my trip to the UK.

## **My wish fulfilled!**

Finally, during my trip I asked for one little indulgence: I wanted to eat a hamburger in a UK MacDonald's – and I was taken there!



Photo: Yuji Kawamura

I want to close my presentation by letting you know that even having dementia you can have such a trip – and remain smiling.

Thank you very much for listening.

\*\*\*\*\*

## What I learnt from accompanying Tomo on his UK trip

Dr Hideki Yamazaki, *Izumi-no-mori* Clinic;

Miyagi 'Dementia Discussion Group' Association



Photo: Eiko Wako

It seems that Tomo-san became more energised every time he encountered people living with dementia in the UK and that from this he obtained true hope and calm courage. This was the trip which made me rediscover the universal significance of people living with dementia meeting other people with dementia – who are positive.

At the same time, this was the trip which forced me to acknowledge that, as a dementia specialist myself, I had been manipulated by the medical model of dementia and insidiously had been in despair.

It was 1990 when I first started to practice in dementia medical treatment. In Japan, since around 1960, government policy to support old age was through a public social medical insurance scheme so people living with dementia were quietly incarcerated in geriatric or psychiatric hospitals – and ended their lives in them. While overlooking this reality, was I myself also in despair? The first meeting about dementia for people with the condition is in fact a meeting with a doctor. However, a doctor without hope can never lend hope to his patients.

With the start of the Long Term Care Insurance scheme in 2000, Japan underwent a huge paradigm shift from the medical model of dementia to a life model of dementia. Along with enhanced home-based services, residential facilities started at last to develop a format for living. We started to see the lives of people with dementia living at home – or in a homely atmosphere within residential settings the feelings and wishes of people with dementia – which previously had been locked in – started to be spoken out.

We invited Tomo-san to a local event in 2014. This was when I first met Tomo-san. I was moved by him – who had been diagnosed with Alzheimer's at the age of 39 and who was in a deep despair but was trying to live positively. However, in Japan there are as yet not many people living positively with dementia like Tomo-san.

On this occasion, by accompanying Tomo-san on his trip to the UK, I learnt that there are many people living positively with dementia there. In addition, I realised during my UK trip that most importantly, people with dementia meet, talk and speak out. Through this, people with dementia notice the right of being independent while coexisting in

their community – and society also notices this. The awareness of this right could lead to ‘living well with dementia’.

I feel that when seeing true hope in people living with dementia my treatment of the condition changes fundamentally. Knowing hope and believing in hope: isn't this most called for in the doctor?

James says:

‘As well as empowering ourselves by finding answers and roads out of despair, we should also empower the professional workers and explain to them that there is life after dementia’ (Weaks et al, 2012. *Perspectives on Ageing with Dementia*, Joseph Rowntree Foundation, p.18).

This was the trip that made me understand profoundly that it is we professionals who should learn hope from people living with dementia.

I would like to emphasise my gratitude to all those people whom I met on the trip. Thank you all so very much.

\*\*\*\*\*

### Comments from Tomo's partner on the UK visit

Eiko Wako, Miyagi 'Dementia Discussion Group' Association;  
Alzheimer's Association Japan (Miyagi Branch)



Photo: Private Collection

After meeting James McKillop, a Scotsman living with dementia, a year ago, our trip to the UK with Tomofuni Tanno was finally accomplished.

In Osaka, James had said to Tomo that 'You are from a different country but you continue to walk alongside me.'

Tomo and I shared the same wish: to know about the country and the environment where James is actively campaigning so

enthusiastically and to meet people there who are living well with dementia.

I was overwhelmed and deeply touched by the comments by those living with dementia I met who stated that they make decisions for themselves about their lives and this was natural for a human being even if living with dementia. I have not heard such comments from those in my own surroundings to date. I asked Tomo if these comments were due to the difference between the two national traits. Tomo replied that, 'I don't think that this is the only reason. It is because of the difference in whether people with dementia are living with confidence.' I felt that what Tomo had been thinking about living with confidence in Japan had now been confirmed after coming to the UK. I thought that when living alongside people with dementia it is so important to listen to and respect the voices of people with dementia and that this will build hope for them.

I feel that by visiting the UK Tomo has found the courage to accept the current situation he finds himself in – and that he has found much hope and he has started to walk together with many of his peers along the pathway to living well with dementia.

\*\*\*\*\*

Translated by Dr Mayumi Hayashi FRSA, University of Edinburgh.



Photo: Private Collection